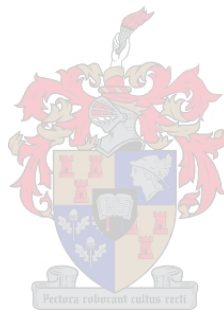


**Parental experiences on the role of wheelchairs in the lives of children with
mobility impairments: A qualitative exploration in Dubai.**

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**Research assignment in partial fulfilment of the requirements of Masters in Human
Rehabilitation Studies at Stellenbosch University**

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Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the authorship owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Anjanet Wanda Liebenberg

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ABSTRACT

Purpose: To explore parental experiences on the role of wheelchairs in the lives of children with mobility impairments in Dubai.

Methods: Seven participants were recruited through purposive sampling and their experiences were explored by conducting semi-structured interviews. The audio recordings were transcribed and thematically analysed.

Results: The findings showed that wheelchairs were an essential part of the children's lives, which enabled their participation in the home, the school and the community. Procurement processes were difficult owing to a lack of assessment and prescription as well as insurance companies providing little assistance with payment. Participants described Dubai as a wheelchair friendly city, and two overarching themes emerged, firstly, Wheelchair: "It is her life", and, secondly, Participation: Isolation versus inclusion

Conclusion: The study is the first of its kind in Dubai and revealed that the wheelchair played an important role in the child's life and allowed participation in life roles that brought joy and fulfilment. Without wheelchairs, children would be isolated and frustrated. However, some of the participants were not satisfied with their child's current wheelchair and felt the chair was not appropriate. It is recommended that the Government of the Dubai develop policies to guide wheelchair service provision in the country. In addition, insurance providers should collaborate with the government to adhere to the policy to ensure healthy lives and promote well-being for all.

KEYWORDS

Wheelchair procurement in Dubai; Parental wheelchair experiences; Children wheelchair participation; Parental satisfaction of wheelchairs.

ABSTRAK

Doel: Om die ouers se ervarings van 'n rolstoel in die alledaagse lewens van hul kinders met mobiliteits beperkings te ondersoek, in Dubai.

Metodes: Semi-gestruktureerde onderhoude is gevoer met sewe deelnemers wat doelbewus geselekteer was. Temas en sub-temas is ge-identifiseer tydens tematiese analise.

Resultate: Die rolstoel het 'n noodsaaklike rol in die lewe van die kinders gespeel. Dit het deelname in die huis, skool en gemeenskap moontlik gemaak. Die verkrygingsproses was moeilik as gevolg van onvoldoende evaluering en voorskrifte. Voorts het mediese versekeringsmaatskappye min of geen finasiele ondersteuning gebied. Deelnemers het Dubai as 'n rolstoel vriendelike stad beskryf. Twee tema's het na vore gekom: 1) Die rolstoel; "Dit is haar lewe" 2) Deelname; Isolasië teenoor insluiting.

Ten slotte: Die studie is die eerste van sy soort in Dubai en het getoon dat die rolstoel 'n belangrike rol speel in die kind se lewe. Dit het kinders toegelaat om deel te neem en hulle gehelp om vreugde en bevrediging te ervaar. Sonder die rolstoel was hulle gefrustreerd en uitgesluit. Deelnemers was nie tevrede met die huidige rolstoele van hul kinders nie en het gevoel dat die rolstoel nie toepaslik was vir hul behoeftes nie. Dit word aanbeveel dat die Dubai regering beleid ontwikkel wat leiding kan bied rondom die voorsiening van rolstoele. Bykomend moet versekeringsmaatskappye, in samewerking met die regering, voldoen aan die voorgestelde beleid om 'n gesonde lewenstyl en welstand vir rolstoel gebruikers te bevorder.

SKEUTELWOORDE

Rolstoel verkryging in Dubai; Ouers se ervaring van die rolstoel; Rolstoel deelname van kinders; Ouers tevrede met die rolstoel.

Introduction

It is essential that children with mobility impairments are provided with appropriate wheelchairs that enable enjoyment of their basic human rights, prevent secondary complications and improve function, participation as well as overall quality of life (WHO 2008; Toro, Eke & Pearlman, 2015; Gudgeon & Kirk, 2015; Visagie, Mlambo, Van der Veen, Nhunzvi, Tigere & Scheffler 2016; Ripat & Verdonck & Carter, 2017). Without wheelchairs, children with mobility impairments will not be able to participate in routine activities such as attending school, joining in family and social outings or taking the dog for a walk. With wheelchairs, they can participate in numerous activities, learn new activities and build experiences such as attending friends' birthday parties, learning adapted sports activities, participating in leisure activities and even travelling to other countries (Evans, 2000; Ripat et al., 2017).

Some wheelchair users perceive the devices as part of their self-identity and, therefore, develop a personal relationship with it. Some see it as an extension of their bodies that brings a significant improvement in activities and feelings of empowerment. Others find it difficult to accept the wheelchair and struggle with feelings of isolation and dependence (Barlew, Secrest Guo, Fell & Haban, 2013; Carver, Ganus, Ivey, Plummer & Eubank, 2016; Ripat et al., 2017). The acceptance or non-acceptance of the wheelchair is often influenced by aesthetics and the appropriateness of the wheelchair features that can either be positively or negatively experienced in the socio-, physical and cultural environments (Ripat et al., 2017) as the use thereof can be enabling or disabling (limiting function as it does not accommodate the users environments) (Papadimitriou, 2008). An appropriate wheelchair provides an optimal fit between the user's needs and the environment, good postural support and ensures overall satisfaction for the user (WHO, 2008; Toro et al., 2015). In addition, a wheelchair should be easily available, safe and durable (WHO, 2008). Furthermore, wheelchairs are best

provided through clearly-demarcated service delivery steps such as the World Health Organisation's (WHO) eight-step wheelchair service delivery plan (WHO, 2008).

In my clinical experience, as Occupational Therapist working at a Paediatric hospital in Dubai, most assistive products like wheelchairs are imported through vendors, who are often sales-orientated business owners that provide assistive technology (AT) products at a high cost. AT is not always provided by a person trained in wheelchair seating to do assessments, prescription, fitting and user training when selling a wheelchair. Finally, the vendors often try to sell their own products, whether appropriate to the users' needs or not. Thus, some users end up with an inappropriate wheelchair.

Based on my clinical observation, insurance companies in Dubai do not always see the provision of AT products as a necessity for the wellbeing of the individual and, therefore, do not offer financial support to procure such equipment. The high cost of services and mobility assistive devices can put a financial strain on the parent (Resch, Mireles, Benz, Grenwelge, Peterson & Zhang, 2010; Toro et al., 2015). Parents do not always have the financial ability and / or therapeutic support to assist with their child's wheelchair related needs and, as a result, are forced to ask for support through means of sponsorship or shop around for the cheapest wheelchair.

Although the Government of Dubai has a vision to provide a disability-friendly city (Morris & Kazi, 2016), children with mobility impairments often suffer the consequences of poor wheelchair procurement processes and environmental barriers, so they might not be able to enjoy this vision. Dubai also has one of the largest growing economies and is known for its big, tall buildings and large shopping malls. Most residents live in two-story villas or apartments in the tall buildings. Public buildings in the UAE are somewhat wheelchair accessible, fitted with wheelchair bathrooms and lifts, but upon entering the building,

wheelchair users are often faced with a curb or steps (Rivano-fischer, 2004). In addition, wheelchair accessible bathrooms are not always built to standard regulations and ramps are often steep and narrow. In terms of education, there are special needs schools and mainstream schools with special needs classes.

The experiences of wheeled mobility users have been explored in several studies and were ably summarised in a meta-analysis by Ripat et al. (2017). However, the experiences of parents of children using wheelchairs remain relatively unexplored. Parents have a crucial role to play in procuring wheelchairs and motivating their children to use wheelchairs. Thus, it is important to understand their views and choices around wheelchairs for their children (Ripat et al., 2017) and the reason why the researcher chose to explore the parental experiences related to wheelchair use of their children.

Literature Review

Themes included in the literature searches were policies and guidelines, the impact of the wheelchair on participation, wheelchair satisfaction, challenges with the procurement process and the role of the parents in the life of a child with a disability (CWD) using a wheelchair. A manual search of books and articles in the Stellenbosch University library and the Google Scholar electronic database were conducted using keywords such as “wheelchair” combined with “children”, “procurement”, “participation”, “satisfaction” and “parental experiences”.

Policies and Guidelines

The UAE is a constitutional federation, which includes a Supreme Council that is the top policy-making body in the UAE. The UAE consists of seven emirates, each with their own ruler in charge of local states and affairs that serve as members of the Supreme Council. The federal government has executive jurisdiction over matters set out in Article 120 of the constitution, which includes health services and education. The local governments have

jurisdiction over matters not assigned to the federal government (Government of the UAE, 2018), but remain in collaboration with the federal authorities. The Ministry of Health and Prevention is the federal health authority under which both Dubai and Abu Dhabi have their own local health authorities (Government of the UAE, 2018).

The late founder of the UAE, Sheikh Zayed bin Sultan Al Nayan's vision was that the entire community should have access to high-quality healthcare (Koornneef, Robben, Seiari & Siksek, 2012). According to Emirati law, which supersedes Dubai government law, employers are required to provide health insurance to employees and their family members (Koornneef et al., 2012). This ensures that 95% of the population are enrolled in a health insurance plan. However, it is not required that health insurance plans make provision for funding of wheelchairs. Although there is an uneven distribution in terms of healthcare service provision to citizens versus non-citizens, 95% of residents have access to primary healthcare (Koornneef et al., 2012).

The Government of Dubai launched a National policy in April 2017 to empower persons with disabilities (PWD) (Government of Dubai, 2018b). This policy adheres to the vision of Dubai by supporting the integration and participation of persons (including children) with disabilities into society (Government of Dubai, 2018a) although there is no mention of wheelchairs or equipment in the policy. However, five key developmental phases were identified from laying down the groundwork and setting a benchmark to implement the design, where stakeholder's roles and responsibilities are clearly defined in support of Dubai's 2021 vision.

On 8 February 2008, the United Arab Emirates (UAE) signed the Convention of the Rights of Persons with Disabilities (CRPD) and ratified it on 19 March 2010. Article 20 of the CRPD declares that a PWD has the right to the highest level of independence through parties ensuring that active measures are taken for personal mobility (UN, 2006). This includes the

provision of appropriate wheelchairs that are available at an affordable cost, with wheelchair training provided by trained professionals (WHO, 2008).

Wheelchair Impact on CWD Function and Participation

Wheelchairs are viewed as enablers of function and active participation that positively influence social integration (Barker, Reid & Cott, 2006). Children with limited walking abilities require a manual and/or a power wheelchair to increase mobility and participation (Rodby-Bousquet & Hagglundharris, 2010). A cross-sectional study conducted in Sweden found that a wheelchair should be introduced at an early age to enable CWD to achieve the highest level of independent mobility (Rodby-Bousquet & Hagglund, 2010).

Most studies reporting on the participation of children using wheelchairs, focused on power wheelchairs (Jones, McEwen, & Hansen, 2003; Gudgeon & Kirk, 2015; Bray, Noyes, Edwards & Harris, 2014). Children, even with severe cognitive and motor impairments, using a power wheelchair can experience autonomous movement, independent wheeled mobility and improved socialisation (Bottos, Bolcati, Sciuto, Ruggeri & Feliciangeli, 2001; Gudgeon & Kirk, 2015).

However, children using a manual wheelchair have also shown improved participation in self-care, mobility, social interaction and play with no negative impact on their motor development (Rodby-Bousquet & Hagglund, 2010; Rousseau-Harrison & Rochette, 2013; Visagie et al., 2016). Caregivers of CWD also value the use of a wheelchair as it provides them with relief, comprises a form of therapy, improves opportunities and enhances the child's participation (Glumac, Pennington, Sweeney & Leavitt., 2009; Rodby-Bousquet & Hagglund, 2010).

With children who are dependent on wheelchairs for mobility, participation can be hindered by social and physical barriers that can lead to exclusion (Connors & Stalker, 2007; Carver et

al., 2016; Ripat et al., 2017). Social barriers include experiences of negative attitudes, humiliation, stigmatisation, pity and invisibility. Uneven terrain, narrow footpaths, lack of or unkempt sidewalks, curbs, stairs and steps, inaccessibility of transport, inaccessible public and home entrances as well as inadequate space inside dwellings are but some of the physical environmental barriers that wheelchair users experience when participating in everyday activities (Van Rooy, Amadhila, Mufune, Swartz, Mannan & MacLachlan, 2012; Carver et al., 2016; Sumner, O'Connell & Macalpine, 2017).

Children who have appropriate wheelchairs, with a good fit to their environment and postural support needs as well as support and acceptance of family, friends and communities can participate and enjoy life with less emphasis on their disability (Ripat et al., 2017). According to the WHO (2008) *Guidelines on the provision of manual wheelchairs in less resourced settings*, the following three aspects should be considered during the assessment and prescription process of an appropriate wheelchair:

- (1) ***Physical needs*** (Health situation, postural and functional needs, body structures).
- (2) ***Environmental needs*** (Where the user lived and where they would use a wheelchair).
- (3) ***Lifestyle needs*** (Things the user needed to do in a wheelchair).

Failure to provide an appropriate wheelchair can cause the child to experience fear, anxiety and isolation (Mukherjee & Samanta, 2005; Gudgeon & Kirk, 2015).

Wheelchair Satisfaction

The personal experience of the wheelchair is another critical factor in function, participation and quality of life (Carver et al., 2016). Even though the wheelchair improves mobility, it can lead to frustration when challenges are encountered and restrictions experienced (Barlew et al., 2013). In addition, where users perceive their wheelchairs negatively, they might reject it (Carver et al., 2016). User satisfaction is affected negatively by wheelchair features such

as the wheelchair providing insufficient postural support, being uncomfortable or too big, adjustments that are made by untrained staff and procurement that supplies inappropriate wheelchairs (Visagie, Scheffler & Schneider, 2013; Carver et al., 2016; Ripat et al., 2017).

As a result, healthcare professionals should advocate for appropriate mobility assistive devices for their patients to increase their overall independence, safety and efficiency (Carver et al., 2016).

Studies in rural parts of Africa have found that challenges during the wheelchair service delivery process can also impact the satisfaction of the wheelchair user (Visagie, Duffield & Unger, 2015; Visagie et al., 2016). Challenges experienced with services and the procurement of equipment can affect the physical and psychological welfare of the parents and the children, preventing them from reaching their optimum levels of function and ultimately impacting the wellbeing of the whole family (Resch et al., 2010; Visagie et al., 2013; Carver et al., 2016).

Wheelchair Service Delivery

According to WHO (2008), provision of an appropriate wheelchair is dependent on eight steps, namely, referral, assessment, prescription, funding, product preparation, fitting and adjusting, mobility training, and a final step comprising of follow-up, maintenance and repairs. By following these steps, accompanied by the involvement of the user and the family, a better fit between the wheelchair, the user and the environment, enabling user-participation and satisfaction can be achieved (Toro et al., 2015; Visagie et al., 2016).

Participation of the user in the procurement process plays a significant role in ensuring user satisfaction with the wheelchair and services received (Carver et al., 2016; Ripat et al., 2017). It also improves functional and mobility outcomes for the user (Glumac et al., 2009; Visagie et al., 2016). When little attention is paid to the users' needs and environments as well as

their aesthetic and feature preferences, users often perceive their wheelchairs negatively (Carver et al., 2016). This might result in devices being neglected or abandoned owing to a lack of client-centered care (Mortenson & Miller, 2008; Carver et al., 2016). Further challenges experienced with the wheelchair service delivery process include long delivery times, not using a holistic approach, incomplete assessments and inadequate procedures during the procurement process (Bray et al., 2016).

Parents in a study conducted in America expressed a need to be instructed on wheelchair use, maintenance and repair (Glumac et al., 2009). Wheelchair skills training that is provided to the user (child) and caregiver (parent) together with overall satisfaction with the wheelchair and services received, can improve mobility and decrease barriers to participation (Visagie et al., 2015; Sumner et al., 2017).

Unfortunately, the implementation of Article 20 and the WHO guidelines are inadequate in many settings and the need for appropriate wheelchairs and services are often not fully met in Dubai as well as in many other countries around the world (Borg, Larsson & Östergren, 2011; Bray et al., 2014; Toro et al., 2015; Visagie et al., 2016;). Many challenges arise surrounding the attainment and use of a wheelchair as described in this review can ultimately put an added burden on parents as they attempt to meet the needs of their CWDs (Hayles, Harvey, Plummer & Jones, 2015). More effective strategies are needed to improve outcomes and services related to mobility independence and participation of children using or needing a wheelchair in Dubai (Bray et al., 2014).

Many wheelchair-related challenges have been observed amongst children who receive outpatient therapy and require wheelchairs for mobility in Dubai. Challenges include finding the right wheelchair, funding for wheelchairs, prolong procurement processes and accessibility in and around the community for wheelchair users. Understanding these challenges, will contribute to how parents can be supported to ultimately enhance

participation of their children using wheelchairs in society (Piškur, Beurskens, Jongmans, Ketelaar, Norton, Frings, Hemmingsson, & Smeets, 2012). Therefore, this study emerged with the aim to explore the wheelchair-related experiences of parents with children needing wheelchairs, who access outpatient therapy services at a children's hospital in Dubai.

Research Method

Design

I worked under the broader paradigm of the subjectivist approach, using an explorative qualitative phenomenological design (O'Leary, 2017) to gain an in-depth understanding into the parental experiences on the role of wheelchairs in the lives of their children with mobility impairments. It is important to recognise and understand the wheelchair experiences of parents within their culture and surroundings (Resch et al., 2010). A descriptive phenomenological design was used as it presented the experiences being studied from the view of the person experiencing it. This research design could produce a wealth of understanding as it permitted the exploration of multiple perspectives and realities through the study of a few cases (O'Leary, 2017).

Population, Sampling, Recruitment and Participants

The study population consisted of parents of children (aged two to 18 years) living in Dubai, who used a wheelchair and who attended out-patient therapy services at a children's hospital in Dubai between January 2018 and April 2018. Carers who attended out-patient therapy services with the child were excluded from the study since the focus was on parental experiences.

Seven parents who fitted the selection criteria were purposefully sampled to participate in this study. Children's ages varied between three and 14, they were from both genders and had varying diagnosis as shown in Table 1.

Table 1: Demographics of the children

	Pseudonym used	Age	Gender	Diagnosis	Education
Child 1	Lona	14	Female	Cerebral Palsy	None
Child 2	Mayed	9	Male	Cerebral Palsy	Mainstream – in special needs class
Child 3	Jeba	13	Female	Muscular Dystrophy	Mainstream
Child 4	Halima	11	Female	Leighs Disease	Special school
Child 5	Ali	3	Male	Cerebral Palsy	Special school
Child 6	Mahmood	7	Male	Cerebral Vascular Accident	None
Child 7	Mosah	6	Female	Genetic Disorder	None

Table 2 shows that both mothers and fathers were interviewed and that in most instances parents were married.

Table 2: Demographics of the participants

	Parent interviewed	Ethnicity	Marital Status	Occupational status:	Home Language
Participant 1	Father	Indian	Married	Employed	Hindi/English
	Mother	Indian	Married	Unemployed	Hindi/English
Participant 2	Mother	Emirati	Divorced	Unemployed	Arabic
Participant 3	Father	Emirati	Married	Employed	Arabic
Participant 4	Father	Palestinian	Married	Employed	Arabic
Participant 5	Mother	Emirati	Married	Unemployed	Arabic
Participant 6	Father	Syrian	Married	Employed	Arabic
Participant 7	Mother	Emirati	Married	Part-time	Arabic

Potential participants were invited to partake in the study telephonically or in person, during this contact provisional consent was obtained and a time and place of the interview was decided on.

Data Collection

Data are collected through one-to-one, semi-structured interviews and a personal information form filled out by the parent (see Appendix B). Interviews were conducted at a venue of the participant's choice, lasted 30-60 minutes and were digitally recorded with the permission of participants. An interview schedule guided the interviews (see Appendix C). Questions on the interview schedule were structured around various wheelchair issues including:

- Child's participation in community, school and family activities
- Process of acquiring the current wheelchair
- Satisfaction with the wheelchair
- Role of the wheelchair
- Dubai as a wheelchair accessible city
- Attitudes and support of others

An interpreter assisted with one participant that was more confident to convey her experiences in Arabic.

Data Analysis

Audio recordings were transcribed by me and reviewed by my supervisor, thereafter inductive thematic analysis was conducted. Thematic analysis was used as it is a flexible, systematic method that allows sorting of data into various themes, allows interpretation of all the meanings of interest in the material, and concludes the findings in a report (Braun & Clarke, 2006). The six steps of thematic analysis described by Braun and Clarke (2006) were

followed, namely, transcribing data, generating codes, searching for themes, reviewing the themes, defining the themes, and generating the report.

Data Rigour

Data saturation was achieved with the completion of the sixth interview, but I continued to conduct one more interview to ensure data reliability. I aimed to report on the data with clarity and employed trustworthiness by publishing only what was reported by the participants. Conclusions drawn from the data were credible as it matched the actual parent experiences as reported by them. As a result, the results of the study were a true reflection of the findings and not influenced by my preferences or judgement. I remained aware of my own thoughts and feelings through reflection and bracketing throughout the research process.

Ethics

The Health Research Ethics committee of Stellenbosch University, reference number 7266 and the Dubai Health care city Authority ethics committee, reference number AJCH-020 approved this study. Written informed consent was received from all the participants prior to data collection. Participants were assured that non-identifiable data would be used and that a copy of the final article would be sent to them after completion. All participant information would be stored, kept confidential and destroyed after five years (Buys, 2017). I remained sensitive to language and cultural barriers, and avoided unnecessary elaboration of culturally-sensitive topics during data collection. I also did not subject the participants to an unnecessary burden of time by asking irrelevant questions (Daniel, 2012).

There was no risk that the study could cause physical harm, but I was careful not to cause psychological harm, by being sensitive towards possible feelings of anxiety, embarrassment and unpleasant memories that might be evoked through the interview (O'Leary, 2017). Basic counselling and debriefing were available, but not required.

Findings

Participants felt that the wheelchair played a significant role in their children's lives and that without it they would be isolated and excluded from participation in everyday living.

Participants agreed that Dubai was a "wheelchair friendly city" and that accessing public places was not the problem, but obtaining an appropriate wheelchair was. Parents were willing to go the extra mile in supporting their children in addressing their needs, but without the financial support of insurance and guidance from service providers, they were left to their own devices.

The data analysis revealed two overarching themes, each with subthemes, as presented in Figure 1.

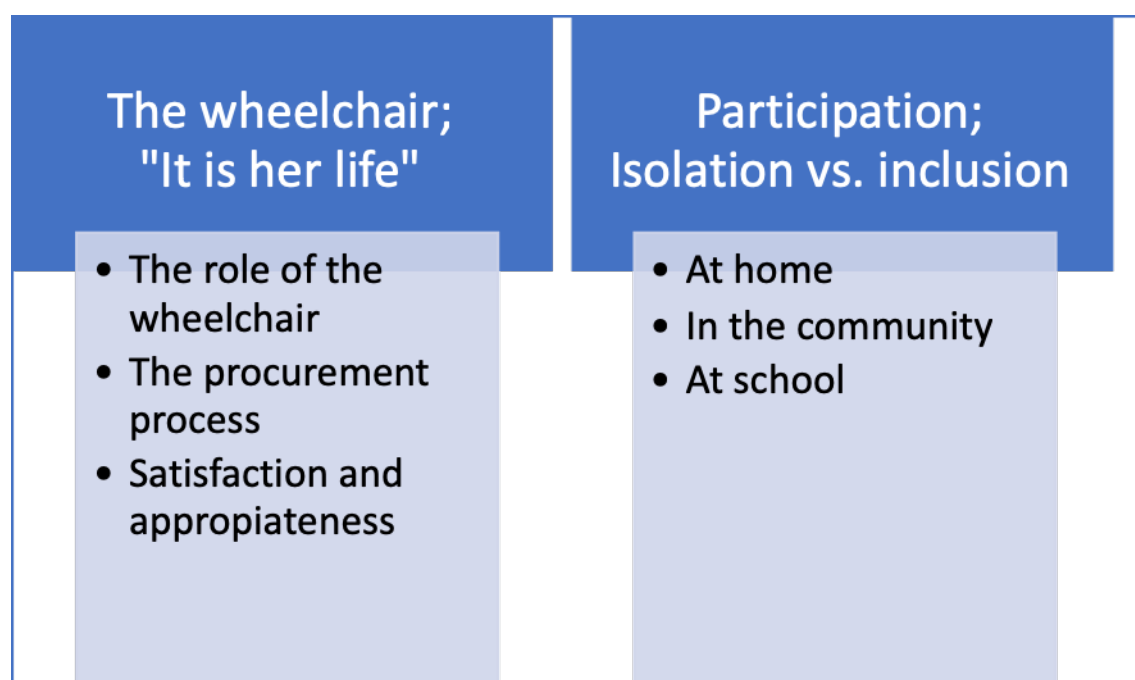


Figure 1: Themes and subthemes identified from the data

Theme 1: The wheelchair: “It is her life”

Role of the wheelchair

Parents explained that with the wheelchair, came freedom. It also allowed independent function and engagement with other children:

Participant 4: “... she cannot move, she cannot go, she cannot sit. It is her life. This wheelchair you know.”

Participant 2: “He will have difficulty to involve himself... like playing with his friends and at school... it helps him to take part.”

Parent narratives spoke of the frustration and unhappiness the children experienced when they were without a wheelchair:

Participant 4: “Sometimes you know, without it, her brother playing, mother in the kitchen and she is shouting, she is crying, that nobody listens... It is very difficult without it... the chair is a must. She cannot manage her life without the chair.”

Participant 5: “He should go outside, he should move around. He needs a wheelchair... like this we give him the life. Without wheelchair, just sitting at the home, he don’t have the right life just sitting and not doing anything. Even he will be not happy.”

All participants reported that their lives would be challenging without a wheelchair. They would have to carry the growing child, with a risk of dropping the child:

Participant 2: “Mayed is 9 years ... and heavy...and big house. He will need someone to carry him... all the time.”

Participant 7: “I need to handle her... maybe she will fall down, and I don’t want this to happen to her.”

Procurement process

The participants found the procurement process very difficult, for example, choosing a wheelchair off the internet or from a catalogue, with no or little support from service providers and paying for the wheelchair out of their pockets:

Participant 3: “... we said ok, let’s go to Dragonmart (Chinatown) and pick a wheelchair. Again, the challenge as a parent...which wheelchair? There was no guideline... of which wheelchair. So, we thought let’s just get her any wheelchair that fits her size and physique.”

Participant 1: “She was growing and she wasn’t fitting in any of the prams or the strollers. The hospital did not suggest ...We saw this company online. We went to the company and the salesman helped us... He is a sales man, so he didn’t know what kind of a chair she wanted. So, we had to describe it to him. We want it this way, that way... we saw this wheelchair on the catalogue... they didn’t have a chair for her to try. They wouldn’t order one. So, we just had to order it randomly. Whether she would fit in that or not later that was to be seen.

About the price, Participant 1 said: “It was too steep...Very pricey...” Others also mentioned the high cost of wheelchairs:

Participant 4: “... a wheelchair is AED 45,000 (\$12,350). It is the earning for some people for a full year, you know... This is very expensive; insurance is not covering.”

The selection of wheelchairs without trying out the actual product led to dissatisfaction with the wheelchair amongst parents even when they found the procurement process itself easy:

Participant 7: “No, it was not difficult [procuring a wheelchair]. I was in [name hospital]. And there is one of the physical therapy, and she told me about this company... She called them... they told me about the wheelchair. They showed me the picture but it’s... they are not honest...what they made for her... it is a little bit different. They bring for me one to see... to look at. Then they bring for me another one, when I got the chair. The cloth of this... at the back... it is not good. Not what I see before. They did not put for her a stand for her head. The cover on the wheels... I told them I want something print. They give me the clear one...also the support from the feet, I didn’t like it.”

Another parent explained the long process of procurement when requesting assistance from insurance:

Participant 3: “... the process was very lengthy until today... more than a year, we still don’t have a chair.”

In contrast, one parent reported that the child was measured by a professional and the insurance (From another emirate, Abu Dhabi) paid for the wheelchair:

Participant 5: “The doctor, make an appointment with the physiotherapy...they told me that he needed a special chair. So, they take the size... And each year they are making it bigger... to his size. Until now... I call the company, and they send me someone to take the measurements and to take it and fix it and make it to his size. No, [in response to the question, ‘Do you have to pay for the wheelchair?’] because

we have the insurance...Thiqa... it is the insurance cover and the government [Abu Dhabi] is paying.”

Satisfaction and appropriateness

Most of the parents were not satisfied with their children’s wheelchairs. Challenges were experienced with the size, weight and durability of the wheelchairs:

Participant 2: “Very big... quickly broken... it affects his back... not in a good way. Because it is not a good measurement for him... and also for his hands... it’s too far for him... the brakes... it is hard for him to use.”

Participant 6: “I don’t like the weight. And for Mahmood it is little big.”

One parent explained that he adapted the wheelchair himself:

Participant 4: “We put something...but this is by ourselves ... to support her. For now it is ok. [The wheelchair] ... it’s large and not completely fit to her. So now it gives some back support. “

Another explained that a therapist adjusted the wheelchair as it could not be returned to the pharmacy from which it was bought:

Participant 6: “... the therapist do a lot of things to the chair. Supporting the legs from down and supporting also from back.”

One participant was very satisfied that her child’s wheelchair accommodated his physical, environmental and lifestyle needs:

Participant 5 (the participant with insurance that paid for the wheelchair): “I am too much satisfied. Why... because I know he is sitting in a safe place. And the

wheelchair is big and strong so it can go any place like the sand.”

Theme 2: Participation: Isolation versus inclusion

Participation and inclusion in the home, community and at school were facilitated by the wheelchair, supportive attitudes, the design and construction of buildings and open spaces as well as private transport. Isolation was experienced due to negative attitudes of extended family and community members, and where design and construction limited access.

At home

The wheelchair made involvement in family activities possible:

Participant 1: “... when I am in the kitchen I take her with me in the chair, she loves being with me.”

Participant 4: “In the house, she can push herself. From the bedroom to the hall. She come... for eating you know... for TV room, dining room.”

However, the construction of the house sometimes prevented access to all areas; resulting in isolation from family activities:

Participant 3: “... we live in a two-story villa... In the past when she was able... to move freely... it was easy. She was able to go up and down as a normal child. Watch TV upstairs, downstairs... she had the freedom... see mom in the kitchen while she was cooking but now... because she is not able to move... she is pretty much stationed in one corner... which is her zone.”

The children were also accommodated outside of the wheelchair in customary activities:

Participant 3: “... we like to as an Arab family sit on the floor to eat. So she has a

small adjusted back... just a chair without the legs. Just the seat. So she will sit there.”

Participant 5: “... we take him and put him and keep him in between us. Because if he stays in the wheelchair he will be far from us” [on the floor for mealtime and family socializing].

In the community

Participants explained that they went on family outings:

Participant 1: “She likes to go out. She likes to visit malls... and she also likes the beaches. We take her to the beach... and she likes to put her feet in the water.”

Participant 4: “... we take her to the park, take her with the chair. Her sister she will try to combine her in all the activity.”

Most of the participants reported on how Dubai as a city accommodated people with disabilities by providing special privileges and accessible public places for wheelchair users:

Participant 2: “Most buildings have slides [ramps]... for wheelchair and lifts... in every government building and parks... and have places for wheelchairs to move. And there are specific entrance for wheelchairs in some buildings.”

Participant 6: “If you will go to any park in the UAE with Mahmood you don’t have to pay any one single dirham. [Mahmood] and his family, I am not paying any one single dirham without showing him any card. If they see this, just Mahmood in the wheelchair they will tell me no need, sorry.”

Participant 7: "... every mall they have like... now in Dubai...they have for handicap. Even in the beach... Jumeirah beach. They got everything for handicap. For example... they make for her a slide [ramp]. On the beach also, we have area for handicap. Also parking. We have special card for her, from the government."

However, public bathrooms did not accommodate all, limiting family time in, for example, a mall:

Participant 1: "They got you know the small, for babies, nappy changes... don't have something bigger, her size. We have to rush home."

Community members were experienced as supportive and helpful:

Participant 4: "... people there [in malls] is very friendly. Very friendly, very kind and supportive. Sometimes they give her something some sweets or they pray for her. She is happy you know, she feels the attention everywhere."

Participant 6: "One time I went to Doctor...teeth Doctor. I took Mahmood there. But the building, it was an old building. There is no slide [ramp] at the back or something you know for the trolley. Two, three guys they help me to carry the chair and put him inside."

However, negative attitudes were also experienced:

Participant 1: "... initially we didn't take her out because of that...the stares. But now we decided that that will not stop Lona from going out. Let them stare... it doesn't matter. But then it does hurt us. Ja it does, it does. And even my second daughter she keeps asking nowadays... why are they looking at Lona like that...why are they staring at her. So, we don't know how to answer her. So... I... We don't want her to get affected... there are other children who are surprised, who ask, ask their mother

what's happened to that child? So, when we hear conversation like that we just want to get out of that place immediately or we want to hide her. Just turn the wheelchair so the people will not upset her. So it's not normal to go to a normal place."

Participant 6: "You know, people on the street is like surprising about Mahmood, 6-7 years old and he is sitting in a wheelchair. It is like always... they cannot belief. And everyone ask me what happened? How come?"

Negative attitudes sometimes left the child, and by implication the family, isolated from community activities:

Participant 1: "... it's difficult to adjust even with family. They cannot cope with a child like this in the house... they cannot cope with her crying, her screaming. So, there is always friction between families, not very welcoming. So, we have to stay on our own. We go for parties and marriages. It's embarrassing, we feel embarrassed. Because the way they look. For them it is like an embarrassment. Our family has a child like this. It's like a taboo kinda thing, they don't welcome. So, we stopped going. So, we don't go even to my grandmother's place, and nobody wants to come and stay with us. Like parents. Even their lives come to a standstill when we ask for help. So, we don't have high expectations, and we understand their situation. So, no bitterness. We just have to get on."

While realising they have no choice but to go on, parents expressed their hopelessness:

Participant 1: "Nobody wants to have a child like this. Your whole life is put to a hold. You cannot do anything else and that's it. Now our lives were great till then. Now no more. There's no life."

Participants found travel in and around town easy as they owned their own vehicles. A special disk entitled them to park on disability parking spaces:

Participant 6: “I have a car... I will carry him to put him in the seat of the car. And put the chair back.”

Participant 7: “We have the special card for her. From the government. She have two cards one for the car and one for the hospital everywhere, because you know first the handicap...it is the first person, you have like for everything. Like when you stand in a line you can be first in line.”

Challenges were faced when travelling abroad using air transport. Parents agreed that services depended on the airline that one travelled with. Some had to carry their children in the airport while others used an airport courtesy wheelchair. Experiences of wheelchairs being broken on arrival at their destination were also related:

Participant 1: “... travelling in the airplane is a very difficult thing... taking her in the aisle, carrying her from the immigration. There is no proper transport like they have the common wheelchair which doesn’t have the strap. They don’t allow the chair inside the airplane.”

Participant 3: “... during traveling we face getting into the plane challenging, especially if you are not travelling with the famous airlines. I carry her into the plane. Depends on the airline, depends on the logistics support of the airport that you have. Of course, in Dubai we are lucky, we have the very best logistics support from the ground staff, in any airport that you are in ... because we need the wheelchair on the second destination, we need to pack it in a good way so that it lands safely. We had an experience that we used the wheelchair inside the airport, so without using the

airport wheelchair, and before you will board into the aircraft they will take the wheelchair. When they deliver it back, it comes like someone opened it... they don't handle the wheelchair in a good fashion. So, what we decided, that whenever we land into an airport, we will use the airport wheelchair. Yes, it is not comfortable, yes it comes in an extra size for my Jeba... but we decided that ok, it is for a short time. And then we at least pack the wheelchair, we wrap it and send it as a check-in luggage. So, at the end of the day, when we land in the destination where we are going we are able to use the wheelchair. It is not broken, nobody tampered with it."

At school

The following narrative illustrated the importance of being included in school activities:

Participant 3: "What I remember... was a competition of a solar power car which Jeba participated in. The fun part for Jeba was the real competition, which was a real race. You have to race your car amongst other students. She had a tiny car compare to the big macho cars... and she won. You have a circle, a race track with all the obstacles and the students would race. The students you know they have the remote control... they have to play with the car. That activity was part of the sport activities. For her it was very nice, she has the cheers, from her fellow students and she... was awarded... not only a trophy but money but still she was so happy that she won."

The wheelchair played an essential role in making it possible to attend school. Still, parents went through lengths to find a suitable school:

Participant 3: "... we face challenges. Even the type of school that we select... we need an elevator. That was the main reason that we had to leave Jeba first school... the

because the schools don't have an equipped... elevator. So, we move to another school."

Another parent reported that his child was without a school for a period as he could not find a school willing to accommodate her needs:

Participant 4: "You know to joining this school, there was many schools that rejected to accept her. Two years we were waiting, just to get her in a school."

School accommodation also came at a cost:

Participant 4: "And very expensive, this year they are saying they will increase the fees 100%. The increase is only for the special group... to do for them special classes, special education."

Challenges were faced when entering the school building, once inside, physical access was usually acceptable:

Participant 3: "Coming out from the car there is a step, you get into the school there is another step and then you reach the first ramp."

Teacher attitudes were positive and many examples were shared on the support they provided to include the children:

Participant 2: "When they make a running competition... the Miss push him and she run with him. The teacher... because they want to involve him in play."

Participant 5: "So she knows that Ali is not totally on the same... vision. So she tries to attract her by her voice, when she speaks, by touching. In the exam... the teacher help him to write... he has to answer and she writes. They are nice at the school."

Special shadow teachers were recommended by schools, which came at a price that further increased the cost of schooling:

Participant 4: "... shadow teacher is a must. And we have to pay for this. And it should not be... like her mother cannot be her shadow teacher."

Discussion

In accordance with literature findings (Sumner et al., 2017; Ripat et al., 2017), the participants felt that the wheelchair was not only seen as their children's legs (extension of their bodies) but as an assistive device that they could not live without. Narratives expressed the fulfilment and joy the child experienced through inclusion in school and family activities, which were possible because of the wheelchair. This was in spite of parents not being satisfied with the wheelchair and the wheelchair features not being appropriate to the needs of the child.

Unfortunately procuring an appropriate wheelchair was not always an easy task. Challenging experiences were revealed under each of the three aspects required when procuring and assessing an appropriate wheelchair:

Physical needs : Poor back and leg support as described by some participants could lead to spinal deformities as could an oversized wheelchair (WHO, 2008). Parents also experienced that their childrens' self-propulsion and applying brakes was hampered if the wheelchair was too wide. One parent revealed that, once bought, the wheelchair could not be returned and therefore adaptations had to be made as best as possible.

Environmental needs It was clear during many of the parents interviews that without considering the environmental conditions, the wheelchair user in Dubai would not be able to move in sand, at the parks and on uneven terrain.

Lifestyle needs The children needed to be able to move in and around the home, participate in school life and enjoy outdoor activities with their friends and families. If a wheelchair was not fitted with the necessary accessories to be safe to use at home, could not fit under a desk in the classroom and was not durable enough for outdoor activities as reported by the participants, their lifestyle needs were not considered (Bray et al., 2014).

The WHO manual (WHO 2008) was developed to guide procurement of appropriate wheelchairs in less resourced settings. However, even in this well-resourced setting of Dubai, where the wheelchair was funded by the user, implementation of the WHO guidelines could have assisted in buying more appropriate wheelchairs.

As indicated, the majority of Dubai's citizens had access to medical insurance. However, in most instances, the cost of the wheelchair was not covered by medical insurance. This might be due to a focus on curative medical care amongst insurance providers and insufficient understanding of the functional and health benefits an appropriate wheelchair provided.

Procurement and durability challenges could be addressed by national policy guidelines. In 2018, the World Health Assembly stated to develop, implement and strengthen policies that would improve the access to AT (Goldberg Pearlman, Rushton & Cooper, 2018). The need to improve the provision of AT, such as wheelchairs was further emphasised by the Global Research, Innovation, and Education on Assistive Technology (GREAT) summit (MacLachlan, Banes, Bell, Borg, Donnelly, Fembek, Ghosh, Gowran, Hannay, Hiscock, Hoogerwerf, Howe, Kohler, Layton, Long, Mannan, Mji, Odera, Perry, Pettersson, Power, Delgado, Slepickova, Smith, Tay-teo, Geiser & Hooks, 2018; Goldberg et al., 2018). The Government of Dubai could improve wheelchair service delivery to its citizens by developing national policy based on international best practice evidence.

A lack of ability to move in and around the community owing to social and physical barriers could cause isolation and feelings of exclusion (Barker et al., 2006, Connors & Stalker, 2007; Carver et al., 2016; Ripat et al., 2018). Participants shared positive experiences related to the design and construction of public places where they enjoyed family outings in Dubai. Dubai's vision of 2021 (Government of Dubai, 2018a) is to transfer the city to be 'friendly' to 'people with determination', the official phrase used in Dubai to refer to persons with disabilities by including and integrating all people into society. Current findings suggest that city authorities were well on their way to achieving this vision through ensuring availability of special parking, lower counters, ramps and/or elevators and accessible bathrooms in malls, parks and other public spaces, especially beaches. This was similar to findings on the accessibility of public buildings in another emirate of the UAE, Al Ain (Rivano-fischer, 2004.), except that one family reported that there was no changing table big enough in the malls for their teenager with spastic cerebral palsy.

Inclusion and integration of children with disabilities extended into the school setting in Dubai. Children with disabilities who can enjoy inclusion in a mainstream school can improve their academic performances, and should function and participate as their peers do when supported by the school (Yeo & Tan, 2018). There were positive reports on accommodations made by the schools, attitudes of teachers, the adaptation of the design and construction of the building and inclusion in school activities with the use of the wheelchair. The challenges included finding suitable schools for the children that could or was willing to accommodate their needs using wheelchairs. It is vital that the school is aware of the needs of the children for them to be able to benefit from mainstream education, however, without the necessary accommodations made, inclusion will be hindered (Russell, 2003; Ohajunwa, Mckenzie, Hardy & Lorenzo, 2014). Negative experiences included broken elevators, desks

too low for a wheelchair to fit under and only limited sporting activities that accommodated a wheelchair user.

Participation was not only limited to the community of Dubai, some parents also travelled to other destinations. Some airlines accommodated wheelchair users through low counters and positive attitudes of personnel. Overall, the experiences with air travel caused a burden on participants. For example, the wheelchair was not allowed beyond a certain point, thus parents had to carry their children, sometimes teenagers, or used a courtesy wheelchair that did not accommodate for the postural support and safety needs of the child. The humiliation of being carried down a narrow aisle can cause negative emotions with a loss of pride, distress and frustration (Darcy, 2012; Bauer, 2018). In some instances, wheelchairs were found damaged on arrival at the destination. Equipment damage could cause a major problem especially if damage occurred on the way to travel destinations, which can end in an unpleasant holiday experience (Darcy, 2012). These barriers infringed on current participant rights to enjoy a memorable travel experiences (Lehto, Luo, Miao & Ghiselli, 2018) and be included in all aspects of society.

Although it was found that the immediate family of the child wheelchair user would go above and beyond to include them and support their needs, the negative attitudes of extended family often caused feelings of exclusion and isolation as well as create disabling barriers (Watermeyer, Swartz, Lorenzo, Schneider & Priestley, 2006). In some cultures, members are urged to help each other, whereas in others, there is stigmatisation owing to belief systems and religion, which can lead to marginalisation (Baffoe, 2013). Dubai is considered a multi-cultural city, where each culture has a unique view on social facilitators and barriers and inclusion of persons with disabilities.

Limitations

My role as a therapist could have influenced the interviewees' responses as they could have been seeking my approval. It was clear that some of the participants struggled to express themselves in English, but the use of an interpreter for one also created challenges as I observed that the interpreter relayed information that was not reported by the participant.

I was also not able to fully relate to or understand the cultural traditions of the families as I am from a different cultural and religious background.

The study only covered a small geographical area, involving only participants residing in Dubai.

Conclusion

The wheelchair played a significant role in the child's life and allowed participation in life roles that brought joy and fulfilment. Without it, the children would be left isolated and frustrated. It was clear from the parents' experiences that they found Dubai a fairly 'wheelchair friendly' city and that they are doing their best to accommodate their children's wheelchair related needs. Most of the participants were not satisfied with the child's current wheelchair and felt the chair was not appropriate. The procurement process of a wheelchair in Dubai was difficult since insurance companies and service providers provided little assistance. The lack of financial support by insurance companies was in contrast with the efforts of city authorities to ensure wheelchair access in Dubai.

Recommendations

- It is recommended that further exploration and research on children with disabilities lived experiences and the travelling-wheelchair-population be done in Dubai.
- It is recommended that the Government of the Dubai develop policies to guide wheelchair service provision in the country. In addition, insurance providers should

collaborate with the government to adhere to the policy to ensure healthy lives and promote wellbeing for all.

- Wheelchair service providers in Dubai should have training that adheres to international standards.

REFERENCES

- Baffoe, M., 2013. Stigma, discrimination & marginalization: Gateways to oppression of persons with disabilities in Ghana, West Africa. *Journal of Educational and Social Research*, 3(1), pp. 187–198.
- Barker, D.J., Reid, D. & Cott, C., 2006, The experience of senior stroke survivors: Factors in community participation among wheelchair users. *Canadian Journal of Occupational Therapy*, 73(1), pp. 18-25.
- Barlew, L., Secrest, J., Guo, Z., Fell, N. & Haban, G., 2013. The experience of being grounded: A phenomenological study of living with a wheelchair. *Rehabilitation Nursing*, 38(4), pp. 193–201.
- Bauer, I., 2018. When travel is a challenge: Travel medicine and the ‘dis-abled’ traveller. *Travel Medicine and Infectious Disease*, 22, pp. 66–72. Available at: <https://doi.org/10.1016/j.tmaid.2018.02.001>.
- Borg, J., Larsson, S. & Östergren, P.O., 2011. The right to assistive technology: For whom, for what, and by whom? *Disability & Society*, 26(2), pp. 151–167.
- Bottos, M., Bolcati, C., Sciuto, L., Ruggeri, C. & Feliciangeli, A., 2001. Powered wheelchairs and independence in young children with tetraplegia. *Developmental medicine and child neurology*, 43(11), pp. 769–777.
- Braun, V. & Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), pp. 77-101. Available at: DOI: <http://dx.doi.org/10.1191/1478088706qp063oa>
- Bray, N., Yeo, S.T., Noyes, J., Harris, N. & Edwards, R.T., 2016. Prioritising wheelchair services for children: A pilot discrete choice experiment to understand how child wheelchair users and their parents prioritise different attributes of wheelchair services. *Pilot and Feasibility Studies*, 2(1), p. 32. Available at: <http://pilotfeasibilitystudies.biomedcentral.com/articles/10.1186/s40814-016-0074-y>.
- Bray, N., Noyes, J., Edwards, R.T. & Harris, N., 2014. Wheelchair interventions, services and provision for disabled children: A mixed-method systematic review and conceptual framework. *BMC Health Services Research*, 14(1), p. 309.
- Buys, M., 2017. Protecting personal information: Implications of the Protection of Personal

- Information (POPI) Act for healthcare professionals. *SAMJ, South African Medical Journal*, 107(11), pp. 954-956.
- Carver, J., Ganus, A., Ivey, J.M., Plummer, T. & Eubank, A., 2016. The impact of mobility assistive technology devices on participation for individuals with disabilities. *Rehabilitation and Disability: Assistive Technology*, 11(6), pp. 468–477.
- Connors, C. & Stalker, K., 2007. Children's experiences of disability: Pointers to a social model of childhood disability. *Disability & Society*, 22(1), pp. 19-33.
- Daniel, J., 2012. *Sampling essentials: Practical guidelines for making sampling choices*. Thousand Oaks: SAGE Publishers Ltd.
- Darcy, S., 2012. (Dis) embodied air travel experiences: Disability, discrimination and the affect of a discontinuous air travel chain. *Journal of Hospitality and Tourism Management*, 19(8), pp. 91–101.
- Evans, R., 2000. The effect of electrically powered indoor/outdoor wheelchairs on occupation : A study of users' views. *British Journal of Occupational Therapy*, 63(11), pp. 547–553.
- Glumac, L.K., Pennington, S.L., Sweeney, J.K. & Leavitt, R.L., 2009. Guatemalan caregivers' perceptions of receiving and using wheelchairs donated for their children. *Pediatric Physical Therapy*, 21(2), pp. 167–175.
- Goldberg, M., Pearlman, J., Rushton, P. & Cooper, R., 2018. The International Society of Wheelchair Professionals (ISWP): A resource aiming to improve wheelchair services worldwide. *British Journal of Occupational Therapy*, 0(0), pp. 1–2.
- Government of Dubai, 2018a. People of Determination. [Online]. Available at: <https://www.dm.gov.ae>.
- Government of Dubai, National policy for the empowerment of persons with disabilities reinforces societal commitment, 2018b. [Online]. Available: <https://www.dsc.gov.ae/en-us/DSC-News/Pages/empowerment.asp>.
- Government of the United Arab Emirates, 2018. [Online]. Available at: <https://www.government.ae/en/about-the-uae/the-uae-government/the-federal-government>.
- Gudgeon, S. & Kirk, S., 2015. Living with a powered wheelchair: exploring children's and young people's experiences. *Disability and Rehabilitation: Assistive Technology*, 10(2),

- pp. 118–125. Available at:
<http://www.tandfonline.com/doi/full/10.3109/17483107.2013.870609>.
- Hayles, E., Harvey, D., Plummer, D. & Jones, A., 2015. Parents' experiences of health care for their children with cerebral palsy. *Qualitative Health Research*, 25(8), pp. 1139–1154.
- Jones, M.A., McEwen, I.R. & Hansen, L., 2003. Use of power mobility for a young child with spinal muscular atrophy. *Physical Therapy*, 83(3), pp. 253–262. Available at:
<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=106836860&site=ehost-live>.
- Koornneef, E.J., Robben, P.B., Al Seiyari, M.B. & Al Siksek, Z., 2012. Health system reform in the Emirate of Abu Dhabi, United Arab Emirates. *Health Policy*, 108, pp. 115–121. Available at: <http://dx.doi.org/10.1016/j.healthpol.2012.08.026>.
- Lehto, X., Luo, W., Miao, L. & Ghiselli, R.F., 2018. Shared tourism experience of individuals with disabilities and their caregivers. *Journal of Destination Marketing & Management*, 8, pp. 185–193. Available at: <https://doi.org/10.1016/j.jdmm.2017.04.001>.
- MacLachlan, M., Banes, D., Bell, D., Borg, J., Donnelly, B., Fembek, M., Ghosh, R., Gowran, R.J., Hannay, E., Hiscock, Hoogerwerf, E.J., Howe, T., Kohler, F., Layton, N., Long, S., Mannan, H., Mji, G., Odera, T., Perry, K., Pettersson, C., Power, J., Delgado, V., Slepickova, L., Smith, E., Tay-teo, K., Geiser, P. & Hooks, H., 2018. Assistive technology policy: A position paper from the first global research, innovation, and education on assistive technology (GREAT) summit. *Disability and Rehabilitation: Assistive Technology*, 13(5), pp. 454–466. Available at:
<https://doi.org/10.1080/17483107.2018.1468496>.
- Morris, S. & Kazi, S., 2016. Planning an accessible expo 2020 within Dubai's 5 star hotel industry from legal and ethical perspectives. *Journal of Tourism Futures*, 2(1), pp. 88–94.
- Mortenson, W. B. & Miller, W.C., 2008. The wheelchair procurement process: Perspectives of clients and prescribers. *Canadian Journal of Occupational Therapy*, 75(3), pp. 167–175.
- Mukherjee, G. & Samanta, A., 2005. Wheelchair charity: A useless benevolence in community-based rehabilitation. *Disability and Rehabilitation*, 27(10), pp. 591–596. Available at: <http://www.tandfonline.com/doi/full/10.1080/09638280400018387>.

- Ohajunwa, C., Mckenzie, J., Hardy, A. & Lorenzo, T., 2014. Inclusion of disability issues in teaching and research in higher education. *Perspectives in Education* 2014, 32(3), pp. 104–117.
- O’Leary, Z., 2017. *The essential guide to doing your research project*. 3rd Ed. London: SAGE Publishers Ltd.
- Papadimitriou, C., 2008. Becoming en-wheeled: the situated accomplishment of re - embodiment as a wheelchair user after spinal cord injury as a wheelchair user after spinal cord injury. *Disability & Society*, 23(7), pp. 691–704.
- Piškur, B., Beurskens, A.J.H.M., Jongmans, M.J., Ketelaar, M., Norton, M., Frings, C.A. & Hemmingsson, & Smeets, R.J.E.M., 2012. Parents’ actions, challenges, and needs while enabling participation of children with a physical disability: a scoping review. *BMC Pediatrics*, 12(1), p. 177. Available at: <http://bmcpediatr.biomedcentral.com/articles/10.1186/1471-2431-12-177>.
- Resch, J.A., Mireles, G., Benz, M.R., Grenwelge, C., Peterson, R. & Zhang, D., 2010. Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology*, 55(2), pp. 139–150. Available at: <http://doi.apa.org/getdoi.cfm?doi=10.1037/a0019473>.
- Ripat, J., Verdonck, M. & Carter, R.J., 2017. The meaning ascribed to wheeled mobility devices by individuals who use wheelchairs and scooters: A metasynthesis. *Disability and Rehabilitation: Assistive Technology*, 13(3), pp. 253–262. Available at: <https://www.tandfonline.com/doi/full/10.1080/17483107.2017.1306594>.
- Rivano-fischer, D., 2004. Wheelchair accessibility of public buildings in Al Ain, United Arab Emirates (UAE). *Disability and Rehabilitation*, 26(19), pp. 1150–1157.
- Rodby-Bousquet, E. & Hagglund, G., 2010. Use of manual and powered wheelchair in children with cerebral palsy: A cross-sectional study. *BMC Pediatrics*, 10(1), p. 59.
- Rousseau-Harrison, K. & Rochette, A., 2013. Impacts of wheelchair acquisition on children from a person-occupation- environment interactional perspective. *Disability and Rehabilitation: Assistive Technology*, 8(1), pp. 1–10.
- Russell, P., 2003. ‘Access and achievement or social exclusion?’ Are the government’s policies working for disabled children and their families? *Children & Society*, 17(3), pp. 215–225.

- Sumner, E., O'Connell, C. & Macalpine, B., 2017. Wheelchair donation in a low-resource setting: Utilization, challenges and benefits of wheelchairs provided through a specialized seating programme in Haiti. *Journal of Rehabilitation Medicine*, 49(2), pp. 178–184.
- Toro, M.L., Eke, C. & Pearlman, J., 2015. The impact of the World Health Organization 8-steps in wheelchair service provision in wheelchair users in a less resourced setting: A cohort study in Indonesia. *BMC Health Services Research*, 16(1), p. 26. Available at: <http://www.biomedcentral.com/1472-6963/16/26>.
- United Nations (UN). 2006. Convention on the Rights of Persons with Disabilities, viewed 26 February 2018, from <http://www.un.org/disabilities/convention/conventionfull.shtml>
- Van Rooy, G., Amadhila, E.M., Mufune, P., Swartz, L., Mannan, H. & MacLachlan, M., 2012. Perceived barriers to accessing health services among people with disabilities in rural northern Namibia. *Disability & Society*, 27(6), pp. 761–775. Available at: <http://www.tandfonline.com/doi/abs/10.1080/09687599.2012.686877>.
- Visagie, S., Mlambo, T., Van der Veen, J., Nhunzvi, C., Tigere, D. & Scheffler, E., 2016. Impact of structured wheelchair services on satisfaction and function of wheelchair users in Zimbabwe. *African Journal of Disability*, 5(1). Available at: <http://www.ajod.org/index.php/ajod/article/view/222>.
- Visagie, S., Duffield, S. & Unger, M., 2015. Exploring the impact of wheelchair design on user function in a rural South African setting. *African Journal of Disability*, 4(1). Available at: <http://www.ajod.org/index.php/ajod/article/view/171>.
- Visagie, S., Scheffler, E. & Schneider, M., 2013. Policy implementation in wheelchair service delivery in a rural South African setting. *African Journal of Disability*, 2(1). Available at: <http://www.ajod.org/index.php/ajod/article/view/63>.
- Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestley, M., 2006. *Disability and social change: A South African agenda*. Cape Town: HSRC Press.
- Yeo, L.S. & Tan, S., 2018. Educational inclusion in Singapore for children with physical disabilities. *Asia Pacific Journal of Education*, 38(2), pp. 175–186. Available at: <http://doi.org/10.1080/02188791.2018.1460253>.
- World Health Organization (WHO), 2008. *Guidelines on the provision of manual wheelchairs in less resourced settings*. World Health Organization, Geneva.

APPENDIX A

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: Parental experiences on the role of wheelchairs in the lives of children with mobility impairments: A qualitative exploration in Dubai.

REFERENCE NUMBER: S18/05/099

PRINCIPAL INVESTIGATOR: Anjanet Liebenberg

ADDRESS: The Polo Residence, Building E1, Apartment 302, Nad al Sheba 1, Dubai

CONTACT NUMBER: 056 450 9551

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are free to withdraw from the study at any point.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and the Dubai healthcare city Authority, and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- The study aim is to explore the wheelchair related experiences of parents of children, needing a wheelchair, that access outpatient therapy services at a children's Hospital in Dubai.
- The study will take place at a time and place that suits the participant. 6-7 Participants

will be included in this study and data will be collected through the completion of a Personal Information form and participation in a semi-structured interview of 30-60 minutes. Questions will be related to the experiences of parents with children in need of a wheelchair. The interview will be audio-recorded with your permission, and transcribed as accurately as possible for the data analysis.

- Most studies related to experience of parents with children with disabilities has been conducted in other countries, not Dubai. The knowledge gained through this study could be used to improve wheelchair related experiences through suggestions made by the parents.

Why have you been invited to participate?

- You have been invited to participate in this study due to the valuable information that you can contribute as a parent of a child in need of a wheelchair, living in Dubai.

What will your responsibilities be?

- Your only responsibility in this study is to complete a short personal information form and partake in a once-off semi-structured interview, during which you will discuss your experience. This will last 30-60 minutes.
- Interviews will be audio recorded with your permission.

Will you benefit from taking part in this research?

- There will be no direct benefit for taking part in this study. However, this study is one of the first of its kind in Dubai, and could lead to a greater understanding of the experiences of parents of children in need of a wheelchair.

Are there any risks involved in your taking part in this research?

- You are at no physical risk.
- The only foreseeable risk is that you might experience emotional discomfort during the interviews, as you will be sharing personal details of your lives and that of your child. Should this happen you will receive counselling from the researcher.

If you do not agree to take part, what alternatives do you have?

- If selected parents do not agree to take part in the study, their out-patient treatment will continue with no changes and no negative feelings from the researcher.

Who will have access to your medical records?

- Any information that is obtained in this study will be treated as confidential and any information that can be connected to a participant will not be disclosed without their

permission. The identity of participants will be kept confidential by assigning a code instead of using their names. Only the researcher and her supervisor will have access to the information obtained during the study.

What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

- Participation in the study will not be charged. No physical contact will be made with the participants or the child and therefore no compensation for injury is available. Participation in the study will be at own risk.

Will you be paid to take part in this study and are there any costs involved?

- You will not be paid to participate in this study; however, you will receive a token of appreciation for your participation, and you will be compensated for any travel expenses.

Is there anything else that you should know or do?

- You can contact the Health Research Ethics Committee at +27 21-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled: Parental experiences on the role of wheelchairs in the lives of children with mobility impairments: A qualitative exploration in Dubai.

I declare that:

- I have read or had read to me this information and consent form in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

Signed at (*place*) on (*date*)2018

.....

.....

Signature of participant

Signature of witness

Declaration by investigator

I (name) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.

Signed at (place)on (date)2018.

.....

.....

Signature of investigator

Signature of witness

Declaration by interpreter

I (name) declare that:

- I assisted the investigator (name) to explain the information in this document to (name of participant) using the language medium of Arabic/English.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (place)on (date)

.....

.....

Signature of interpreter

Signature of witness

APPENDIX B

PERSONAL INFORMATION

Instructions: *Please fill in your personal information. Indicate your choices by circling the correct option.*

Name and Surname:

1) Gender: Male/ Female

2) Ethnicity: Emirati/South Asian/Indian/Egyptian/Other

If other, please specify:

3) Marital Status: Single/Married/Divorced/Other

4) Home language:

5) Occupation: Part-time/ Full-time/ Unemployed

6) Age of your child using a wheelchair:

7) Disability of your child:

8) Onset of disability: Congenital/Acquired (after birth)

9) Gender of child: Male/Female

10) Does your child have a wheelchair: Yes/No

11) How long has your child been using the wheelchair?

12) Is your child in school: Yes/No. If Yes, Special/mainstream

APPENDIX C

INTERVIEW SCHEDULE

1. You have brought some photographs related to your child with a disability and/or in a wheelchair. Would you like to show them to me and explain them?

2. Do you help you child with any activities, not limited to home?

(PROBE QUESTIONS)

- Help with transfers/dressing/pushing the wheelchair/other activities?
- Are you a stay at home parent?
- What are your weekly responsibilities for your child?
- E.g. Take child to school, therapy, and doctors' appointments

3. How did you feel when you found out that your child struggle to/cannot walk and might need a wheelchair?

4. If your child has a wheelchair please tell me about how you got the wheelchair?

(PROBE QUESTION)

- Was it difficult to get the wheelchair?
- Tell me about the process?
- Who, if anybody helped you?
- How/where did you get the chair?
- Did you find it reasonably priced? Who paid for it?

5. If your child does not have a wheelchair – what has been preventing your child from getting a wheelchair?

6. How do you find the wheelchair?

On a satisfaction scale, how satisfied are you with your child's current wheelchair?

Not at all satisfied – Moderately satisfied – Very satisfied

(PROBE QUESTIONS)

- Tell me about your likes/dislikes?
- Does it help your child to move around?
- Does it support to your child's body/needs?
- Are you happy with its size?
- How happy are you with its weight?

7. How does your child move around?

(PROBE QUESTIONS)

- In the house?

- Going to friends?
- The mosque or other places around town?

8. Are there anything you and your family like to do together?

(PROBE QUESTIONS)

- Can your child using a wheelchair join in the activities?
- What role does the wheelchair play in that?
- Does the wheelchair help your child do more things with the family? Please explain
- Are there any barriers that prevent your child from partaking in these activities?

9. Do you think Dubai is a wheelchair friendly city?

(PROBE QUESTIONS)

If yes, why? If no, why not?

Can your child move around the city with the wheelchair as s/he wishes?

10. How do people on the street react to your child?

(PROBE QUESTIONS)

With a disability?

Using a wheelchair?

11. Is your child attending a school?

(PROBE QUESTIONS)

- Does the wheelchair accompany the child to school? If not how does the child move in school? If yes, does it help?
- What is the attitude of the teachers towards the child in the wheelchair?
- Do the teachers make any accommodations for your child?

12. Are there any challenges that you experience as a parent of a child that needs a wheelchair?

(PROBE QUESTIONS)

- If so what are the main challenges?
- Are there transport difficulties?
- Are there financial difficulties?
- Environmental difficulties?

13. How would your child's (Name of the child) life be different if he/she did not have a wheelchair?

14. How would your life be different if your child did not have a wheelchair?

APPENDIX D



Health Research Ethics Committee (HREC)

Approval Notice

New Application

28/08/2018

Project ID :7266

HREC Reference #: S18/05/099

Title: Parental experiences on the role of wheelchairs in the lives of children with mobility impairments: A qualitative exploration in Dubai

Dear Ms Anjanet Liebenberg,

The New Application received on 02/07/2018 12:12 was reviewed by members of Health Research Ethics Committee 2 (HREC2) via expedited review procedures on 28/08/2018 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: This project has approval for 12 months from the date of this letter.

Please remember to use your Project ID [7266] on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Please note you can submit your progress report through the online ethics application process, available at: [Links Application Form Direct Link](#) and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/Index/7266>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Francis Masiye,

HREC Coordinator,

Health Research Ethics Committee 2 (HREC2).

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)-REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)-IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the [World Medical Association \(2013\). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects](#); the South African Department of Health (2006). [Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa \(2nd edition\)](#); as well as the Department of Health (2015) Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.



June 6th, 2018

Anjanet Liebenberg
Al Jalila Children's Specialty Hospital
Dubai

Study Title: Parental experiences on the role of wheelchairs in the lives of children with mobility impairments: A qualitative exploration in Dubai - AJCH-020

Dear Ms Anjanet Liebenberg,

Further to your submission of final documents on Thursday May 29th, 2018 to progress confirmation of Dubai Healthcare City Authority – Regulatory (DHCR) ethical approval for the above-mentioned study.

Decision – Approval

I am pleased to inform you that the study has been approved, and so you may proceed with the project. However, the REC suggests that a statement be added to the study protocol that clearly states that audio recordings of participant interviews will also be destroyed. With regards to the project, increasing the sample size may add more value to the study design.

General Conditions/Guidelines:

1. It is expected that all conditionally approved or approved research projects start within 6 months of the date of the REC letter. If you were not able to start the study within this timeframe, you will be required to resubmit your application or justify the reasons.
2. For monitoring purposes, representatives of the DHCR Research Office can come for a site visit at any time.
3. You should notify DHCR should you deviate or make changes to the approved submission protocol and request an amendment to the application.
4. You must alert DHCR if significant incidents/developments occur in relation to the safety of the individuals enrolled in the study.
5. Notification of any serious breaches of the protocol should be made in writing to DHCR within 15 days.
6. Study termination i) in case of premature termination of the study, DHCR must be notified within 30 days of termination. ii) in case of a planned termination/end of the study, DHCR must be notified within 60 days of its conclusion.
7. Submit an Annual progress report and a final report to the DHCR Research Office.
8. Please note failure to comply with clauses 7,8 and 9 may result in suspension.
9. You undertake full responsibility in respect of ensuring the ethical and scientific quality, health and safety, confidentiality and financial probity of this protocol.

Dubai Healthcare City Authority, P.O. Box: 505001, Dubai, UAE
T +971 4 383 8300 F +971 4 383 8359

سلطة مدينة دبي الطبية، ص.ب: ٥٠٥٠٠١، دبي، الإمارات العربية المتحدة
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dhcr.gov.ae



The approval is valid in the following organization:
Al Jalila Children's Specialty Hospital, Al Jadaff, Dubai

Statement of Compliance

DHCR is authorized to conduct ethical review of research studies and is constituted in accordance with Research Governance Arrangements and is fully compliant with regulations, conditions and principles of good clinical practice.

Please feel free to contact _____ – Research and Policy Development via
email at _____ or the DHCR Research Department at
research@dhcr.gov.ae if you have any further queries.

Kind Regards

Chairperson

DHCR Ethics Review Committee

Dubai Healthcare City Authority, P.O. Box: 505001, Dubai, UAE
T +971 4 383 8300 F +971 4 383 8359

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